

End of Life Care in Liver disease. BASL SIG meeting 20.03.2019 Bristol.

Minutes, commentary and actions

AGENDA

0930 - 1000 Tea, coffee & biscuits on arrival

1000 – 1015 Introduction – Mark Wright

1015 – 1035 Development of a 'Question Prompt List' – Joe Low

1040 – 1100 Encouraging patient participation in advance care planning – Roberta Jordan

1105 – 1125 Improving symptom control in advanced liver disease – Bonita Stevens

11.30 – 1150 Tea, coffee & biscuits

1150 – 1220 Preparing for the end stage: Living with kidney disease – Barny Hole

1230 – 1240 Education Group update – Fiona Finlay

1250 – 1300 Website and resources update – Hazel Woodland

1300 – 1345 Lunch

1345 – 1415 General discussion:

This was a well attended meeting with excellent research and progress presentations.

Discussions in the morning after each talk, and then during the general discussion after lunch have led to a number of action points outlined below.

This is the end of the 2nd year of this SIG and Mark Wright will be stepping down as lead to make way for Ben Hudson. It's an exciting time as this is a field that is coming alive and we are already making progress.

Many concepts have been explored and the framework for future end of life care established. There is some really good quality research coming through which will fill in details for this framework.

While this research is ongoing it is important that we keep the momentum we have built and to scale up our ideas to reach patients nationwide. The actions proposed below are designed to prioritise this.

As part of the general discussion we pondered 3 main questions which form the headings in the pages that follow.

1. What have we achieved so far?

- Growing membership of the most long established BASL SIG.
- We have helped to legitimise palliative care as part of patient management in ESLD with colleagues locally.
- Awareness and understanding of difficulties providing palliative care/ anticipatory care plans in hepatology compared to other specialities.
- Culture change with integration of liver and palliative care definitions
- Cross working between hepatology and palliative care,
- We have put end of life care in liver disease on the agenda
- Good local projects and engagement for those members involved in the SIG
- Established a forum for information sharing.
- Established a forum for collaborative research/ quality improvement projects
- Established a source of PPI for future research
- Established a forum for producing national audits
- Established a forum for producing national guidelines
- Established links with charities- BLT, LIVER NORTH etc.
- Produced a BASL website presence- position statement, shared documents. Visibility, Legitimacy
- Produced the “thinking ahead” document with BLT
- Regular meetings for all of the above
- Established an education subgroup- evolving
- Established a useful set of trigger questions
- Established nurse led paracentesis as a foundation for good end of life care in hospitals.

2. What have we still to achieve?

- Defining the ideal service model for end of life care in liver disease in parallel with the management of decompensated cirrhosis
- Standardising care across centres- evidence, guidelines, funding, triggers, pathways
- Breaking into DGHs and hospitals with non-specialist gastroenterology
- Adopting practices/ ownership of general palliative care
- Standardised referral guidelines
- Uniform methods for patient identification (although working interim models)
- Establishing end of life care as part of the transplant waiting list management
- Establishing a national data base- registry, numbers for research, KPIs
- Firming up support from other services eg. Community substance misuse, homeless health care, GPs, community CHSs
- Standards/ measures/ KPIs- parallels with nephrology
- Education of colleagues (a work in progress)
- Integration into curriculum, MRCP gastro exit exam
- Integration into IQILS + Define Metrics
- Wider spread Conference presence
- Publications in *Hepatology* journals (as opposed to palliative care journals which hepatologists tend not to read)
- Understanding by hepatologists of the research tools used in this field
- Establishing the points at which end of life care conversations are had (distinct from at which point referral to palliative care takes place)- separate out the 2 of them.
- Overcoming the paradox of a “special” interest group when we are trying to make this a part of “general” hepatology
- Avoidance of “care leading to end of life” when providing “end of life care”- the risk of integrating this work with decompensated care bundles
- Convert “soft power” influence- persuading colleagues within our own institutions, regions and nationally into “Hard power”- KPIs and mandatory behaviours

3. What are we going to do next?

- Design a National scoping tool- what isn't being done- fill gaps
- Each hospital to identify their own gaps 1st.
- Identify Targets to be achieved for next meeting.
- Increase involvement of GPs and Patients/carers in the SIG
- Update the decompensated liver disease care bundle to include palliative care plan, include a check box to ensure Dr completing has checked for existence of anticipatory care plan.
- Finesse and disseminate screening tool.
- Set up palliative training event specifically for hepatology trainees.
- Set up hepatology training event specifically for palliative trainees.
- Establish local network groups.
- BASL Poster to show what we have achieved
- Target BASL with lots of end of life care posters to show the work we are doing.
- State of art plenary in a near future BASL- de mystify end of life care, role of palliative care, methodology of palliative care research
- Minimum data set including end of life care information for clinic letters and discharge summaries
- Develop media platforms. Video productions, downloadables
- Develop registry of decompensated liver disease.
- Further analysis of "voices" data regarding liver disease (previous one was up to 2015 before this SIG)
- Attitudes survey/ questionnaire via BASL/BSG
- Audit in participating centres, or by the 16 NTN trainees for all deaths in a time frame- conversation about prognosis, offer of ACP discussion, place of death.

Workstreams identified

Themes

1. Stable base established but with work still to do
2. Need for “breakout and scalability” Soft and Hard Power solutions
3. Definitions of Message
4. Culture change-Need for education, normalisation of end of life care in liver disease
5. Need for evidence/data to support service development and arguments
6. Research

1. Stable base established with some work still to do

- Finesse and disseminate screening tool. **(volunteers please)**
- Design a National scoping tool- what isn't being done- fill gaps **(see below- ? feedback at next meeting)**
- Each hospital to identify their own gaps 1st. **(all)**

2. Need for “breakout and scalability” Soft and Hard Power solutions

“Soft”

- Meetings with local hospitals in our networks **(all)**
- Meetings with local community partners **(all)**

“Hard”

- Inclusion of end of life care Metrics in IQILS **(Ben H?)**
- End of life care in liver disease CQIN **(Volunteers?)**
- Modification of decompensated care bundle **(MW, BH to write to Mark Hudson and Andrew Austin)**
- Insertion of end of life care module into the curriculum an MRCP gastro exit exam **(Fiona Finlay, MW and BH to write to curriculum organisers)**

3. Definitions of Message

- Establishing the points at which end of life care conversations are had (distinct from at which point referral to palliative care takes place)- separate out the 2 of them. **(volunteers please)**
- Paradox of a “special” interest group when we are trying to make this a part of “general” hepatology

4. Culture change-Need for education, normalisation of end of life care in liver disease

- Set up palliative training event specifically for hepatology trainees. **(All)**
- Set up hepatology training event specifically for palliative trainees. **(All)**
- Develop media platforms. Video productions, downloadable Apps **(Sarah, Bonita?)**
- Tool kits for prescribing **(Hazel, Wendy?)**

5. Need for evidence/data to support service development and arguments

- Develop registry of decompensated liver disease. **(MW talk to Paul Roderick?)**
- Further analysis of “voices” data regarding liver disease (previous one was up to 2015 before this SIG) **(Roberta Jordan- was this something you could access?)**
- Attitudes survey/ questionnaire via BASL/BSG. (questions to be defined)- **(Volunteers?)**
- Audit in participating centres, or by the 16 NTN trainees for all deaths in a time frame- conversation about prognosis, offer of ACP discussion, place of death. (questions to be defined) **(Volunteers?)**

6. Research

- BASL Poster to show what we have achieved. **(Volunteers)**
- Target BASL with lots of end of life care posters to show the work we are doing. **(ALL)**
- State of art plenary in a near future BASL- de mystify end of life care, role of palliative care, methodology of palliative care research. **(MW, BH write to BASL conference organising committee)**